



Questions and Answers

Submitted to the

**United States Department of Health and Human Services
Health Information Technology Policy Committee
Certification/Adoption Workgroup**

by

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Commission on Law and Aging
American Bar Association**

**Virtual Hearing
September 23, 2013**



Co-Chairmen Marc Probst and Larry Wolf, and Members of the Committee:

I am Charles P. Sabatino, Director of the American Bar Association's Commission on Law and Aging, and I am pleased and honored to appear today on behalf of the ABA. The ABA, with nearly 400,000 members, commends the Office of the National Coordinator for Health Information Technology of the U.S. Department of Health and Human Services for holding this hearing.

The ABA has strongly promoted the value of advance care planning and the use of advance health care directives by all adults since the mid-1980s. In our two most recent policies, we urge widespread support of protocols such as Physicians Orders for Life-Sustaining Treatment (POLST) and strengthening of the Patient Self Determination Act. A complete record of ABA policies on health decisions is attached.

We appreciate the opportunity to offer the following information in response to the questions of the Certification/Adoption Workgroup, based upon more than 25 year of tracking state developments in health decisions laws through the ABA's Commission on Law and Aging:

QUESTION: What has been the experience thus far with the implementation of advance directives? What is working? What is needed?

RESPONSE:

Advance directives, as used here, means a legally recognized document that appoints a health care agent or proxy, or that provides instructions or guidance about critical medical decisions relating to life support and palliative care.

We know that only about a third of all adults have a health care advance directive, although that number does increase with age. A Jan. 2008 AARP Bulletin poll "Getting Ready to Go" found that the percentage of persons reporting that they had a health care power of attorney was 24% for those age 35-49; 39% for those age 50-59; and 51% for those 60 or older.

Unfortunately, just having an advance directive does not ensure that the individual's wishes will be known or respected by health care providers. There are many reasons for this, including the fact that healthcare providers often don't know that the directive exists; or if they do know, it's not available in the medical record or easily accessible. Moreover, instructional advance directives (i.e., living wills) usually contain boilerplate instructions to general hypothetical situations and do not normally provide very useful clinical guidance in complicated, real-time medical situations that may occur long after a directive was executed.¹

We do know that the appointment of a health care agent or proxy improves the decision-making process, from both the provider's and agent's perspectives, because it clarifies who should be directly involved in the decisions at the time decisions need to be made and allows

¹ Charles P. Sabatino, "The Evolution of Health Care Advance Planning Law and Policy," 88(2) Milbank Quarterly 211-239 (2010).

the decision-maker to weigh all the facts and options in real time. However, merely having an appointed agent does not necessarily mean that the agent is well-informed about the patient's goals and wishes or engaged effectively in decision-making on behalf of the patient.

The process that does clearly make a difference is the level of advance care planning communication that takes place during a course of treatment. Advance care planning is an iterative process that is broader and less legally focused than that of advance directives. Advance care planning, or ACP:

encompasses not only preparation of legal documents but also discussions with family members and physicians about what the future may hold for people with serious illnesses, how patients and families want their beliefs and preferences to guide decisions..., and what steps could alleviate concerns related to finances, family matters, spiritual questions, and other issues that trouble seriously ill or dying patients and their families.²

Advance directives play a role in ACP and can be one of the tools to document ACP. But it is not the only tool for documenting ACP. The result of ACP is a clear plan of care for the patient that is consistent with the patient's values, goals of care, and wishes.

Medical notes written or dictated by the physician that reflect a discussion with the patient regarding goals of care, treatment preferences, or related decisions can be just as effective as a formal advance directive.³ In at least 15 states, if these medical notes are properly witnessed, they actually constitute a formal advance directive.⁴ Another form of documenting, as well as prescribing a care plan for patient's with serious progressive chronic conditions, is the protocol commonly called Physician Orders for Life Sustaining Treatment (POLST).

The POLST Program, known by a variety of names,⁵ is in use or development in a majority of states. POLST is a clinical process designed to facilitate communication between health care professionals and patients with advanced illness (or their authorized representatives) that facilitates shared, informed medical decision-making. The result is a set of visible, portable medical orders that is applicable in all settings and across care transitions, is reviewable, and respects the patient's goals for care in regard to the use of cardiopulmonary resuscitation (CPR), breathing machines, and other interventions. POLST does not encompass the entire

² Institute of Medicine, Committee on Care at the End of Life, Approaching Death: Improving Care at the End of Life 198-99, ed. M.J. Field and C.K. Cassel (1997).

³ P. Kernerman, D.J. Cook & L.E. Griffith, "Documenting Life-Support Preferences in Hospitalized Patients," J Crit Care. 1997 Dec;12(4):155-60.

⁴ Charles P. Sabatino, "The Evolution of Health Care Advance Planning Law and Policy," 88(2) Milbank Quarterly 211, 226 (2010).

⁵ POLST originated in Oregon, but examples of the program using differing names include West Virginia's Physicians Orders for Scope of Treatment or "POST" and New York's Medical Orders for Life-Sustaining Treatment or "MOLST."

plan of care; rather, it creates an actionable plan of care that addresses the high probability critical decisions the patient is facing.

Research on the POLST program confirms that it improves documentation of a range of treatment preferences and is associated with low rates of unwanted hospitalizations.⁶

QUESTION: As part of advance care planning, what information should be included in or with a patient's advance directive? A POLST/POST/MOSLT form, care planning notes, other?

RESPONSE:

In answering this question, it is important to distinguish **tools** of advance care planning from **outcomes** of advance care planning. The ultimate outcome of ACP is a clear **plan of care** for the patient that is consistent with the patient's values, goals of care, and wishes. A plan of care may take three forms:

- In a hospital, the plan of care is normally reflected in the medical record and consists of medical notes and prescriptive treatment orders.
- For certain types of care such as nursing home care, home care, hospice, and others, a formal documented plan of care is required for coverage by Medicare, Medicaid, and some private insurance.
- For patients with serious, progressive conditions or frailty, POLST or physician orders for life-sustaining treatment may be the plan of care for critical decisions.

The POLST Program, known by a variety of names,⁷ is in use or in development in a majority of states. The result is a set of visible, portable medical orders on a standardized form that is applicable in all settings and across care transitions, is reviewable, and respects the patient's goals for care in regard to the use of CPR, breathing machines, and other interventions. POLST does not encompass the entire plan of care; rather, it creates an actionable plan of care that addresses the most critical decisions the patient is facing.

The tools of advance care planning also number three:

- Advance directives are the most well-known tool of advance care planning, both for spurring the discussion and document the individual's values, goals, and wishes.
- Medical notes written or dictated by the physician that document a discussion with the patient regarding goals of care, treatment preferences, or related decisions can be

⁶ Susan E. Hickman, et al., "A Comparison of Methods to Communicate Treatment Preferences in Nursing Facilities: Traditional Practices Versus the Physician Orders for Life-Sustaining Treatment Program," J Amer. Geriatrics Soc. 2010 Jul ;58(7):1241-8.

⁷ POLST originated in Oregon, but examples of the program using differing names include West Virginia's Physicians Orders for Scope of Treatment or "POST" and New York's Medical Orders for Life-Sustaining Treatment or "MOLST. POLST is a clinical process designed to facilitate communication between health care professionals and patients with advanced illness (or their authorized representatives) that facilitates shared, informed medical decision-making.

- just as effective as a formal advance directive.⁸ In at least 15 states, if these medical notes are properly witnessed, they can actually constitute a formal advance directive.⁹
- Finally, POLST is not only an outcome of advance care planning, it is also a tool for engaging in advance care planning for those patients with serious, progressive chronic conditions or frailty.

The ABA suggests that any process for documenting advance directives must be equally attentive to documenting advance care planning discussions with patients or their surrogates and POLST forms. Comparing the care actually received with these indicia of the patient's wishes is the only effective way to determine the extent of "patient-centeredness" of one's care. I have attached a copy of comments on "meaningful use" standards that the ABA submitted in January 2013, which elaborates further on this.

QUESTION: In consideration of the previous question, how could the meaningful use measure for advance directives be improved? The measure is labeled: *Record whether a patient 65 years old or older has an advance directive*. Additionally, do any legal implications arise from removing or changing the age threshold?

RESPONSE:

While it is true that the likelihood of disability and death statistically increases for the population as a whole as one ages, age is a poor proxy for need for advance care planning. Age 65 is an arbitrary figure related to little more than the age of eligibility for Medicare.

The value of ACP increases as individuals advance in their care needs and especially as they approach death. Most 65 year olds are quite healthy, and about 28% of deaths in the United States happen to persons under age 65.¹⁰ Raising the age merely means that larger numbers of persons facing advance care will be left out of the equation.

Most deaths today occur after a period of chronic, progressive illness,¹¹ which should be a conspicuous trigger for advance care planning. The challenge is how to capture that population meaningfully in the functioning of electronic health records. Short of a convenient diagnostic marker¹² that could trigger documentation of advance care planning, the only

⁸ P. Kernerman, D.J. Cook & L.E. Griffith, "Documenting Life-Support Preferences in Hospitalized Patients," J Crit Care. 1997 Dec;12(4):155-60.

⁹ Charles P. Sabatino, "The Evolution of Health Care Advance Planning Law and Policy," 88(2) Milbank Quarterly 211, 226 (2010).

¹⁰ Centers for Disease Control and Prevention, Death in the United States, 2009 NCHS Data Brief, No. 64 (July 2011). See: <http://www.cdc.gov/nchs/data/databriefs/db64.pdf>

¹¹ Centers for Disease Control and Prevention, "Chronic Diseases are the Leading Causes of Death and Disability in the U.S." See: <http://www.cdc.gov/chronicdisease/overview/index.htm>.

¹² Conceptually, some agreed upon diagnostic or functional marker could be used to define this population. A very simple example would be the need for significant assistance with two activities of daily living. This is a common trigger used by the insurance industry for long-term care insurance coverage.

reliable alternative is a post-mortem look back. Most individuals who die during a reporting period should have had the opportunity and encouragement to engage in advance care planning. So for that population, one would expect to find in their medical records either an advance directive, advance care planning clinical notes, or a POLST form.

QUESTION: What concerns, if any, does an electronic environment (use of EHRs and HIE) introduce for advance directives (e.g., a transition of care)?

RESPONSE:

Transitions of care can be categorized in three domains: time, place, and disease. With respect to time, ensuring the currentness of one's wishes expressed in any documentation of ACP is a challenge. As noted earlier, ACP is an iterative process. One's goals of care are likely to change as one's condition worsens or improves. Changes in patients' preferences as their conditions change have been shown to be common, and indeed, expected.¹³ Thus, ensuring timely and accurate updates of advance care plans in the medical record is a concern.

With respect to place, transitions of care from one venue to another often precipitate a failure of continuity in one's treatment plan. The new facility's policies, clinical procedures, and care routines will likely vary from the transferring facility. Without a common and accessible source of knowledge about the patient's plan of care and personal preferences, care may default to repetitious or non-patient centered modalities.

With respect to disease, the reality of longevity typically brings with it multiple chronic conditions for which one receives the care from specialists for virtually each organ of the body. The transition from one doctor to another for different conditions also suffers from the loss of continuity of care. That deficit could be ameliorated by ensuring that all have timely access to the individual's overall care plan and treatment goals.

- What type of privacy and security issues exist for advance directives?

RESPONSE:

Since the conventional advance directive is created by individuals on their own time and in their own place, they are initially in control of the extent to which privacy is important. They choose with whom to share their directive. Once a directive (or ACP notes, or POLST) is in the medical record, the privacy issues are essentially no different than the privacy issues of other elements of the patient's medical record.

The security issues are essentially the same as the transition issue discussion above--that is, the challenge of ensuring timely and accurate updates of advance care plans in the medical record.

¹³ See, e.g., Terri R. Fried et al., "Changes in Older Persons' Preferences Regarding Treatment Outcomes Over Time," 166(8) *Arch Intern Med.* 890 (April 24, 2006).

- Are there any requirements for the length of time an advance directive must be maintained in the information system?

RESPONSE:

There are currently no requirements in law or regulation that we are aware of. But there is a practical concern about staleness, again because of the iterative or developmental nature of ACP. If a person's state of health has remained fairly steady over a long period of time, you would not necessarily expect his or her advance directive to change significantly. But for a person who has experienced a litany of new and significant health events, concern over the accuracy of a ten-year-old directive would be justified.

A rule of thumb in education about ACP is that one's directive should be reviewed at least when any of the five "D's" occur:

- Decade of time passes;
- Death of a loved one is experienced;
- Divorce from one's spouse;
- Diagnosis of a new and significant condition; or
- Decline in one's functional capacity.

The timeliness of POLST forms is even more important than the timeliness of advance directives, because POLST is directed to the individual's current condition, characterized by serious, progressive illness. By definition, the individual's condition is progressing toward end-stage and not stable, so care plans are more likely to change.

One health system has looked at the currentness of advance care plans in their electronic medical records -- Gunderson Lutheran Health System in La Crosse, Wisconsin. A retrospective evaluation of Gunderson's advance care planning processes published in 2011 found that 90 percent of a sample of 400 deceased patients had advanced directives, and 99.4 percent were available in the electronic medical record. On average, the directives were 3.8 years old. The study also found that 67 percent of decedents had a POLST form in the record. The median age of the last POLST in the record was 4.3 months before death.

QUESTION: What legal implications arise with a transition of care (e.g., the use of an advance directive or POLST by another provider, across state lines, etc.)?

RESPONSE:

Of the nearly 20 states that have operationalized POLST, virtually all expect health care providers to recognize POLST form signed by another health care provider, even one that is not credentialed by the receiving facility. The expectation is either a regulatory requirement or a grant of immunity for doing so in good faith. But note, this does not mean automatic, mechanical compliance. It only means that, if there is no time to engage the patient or an authorized surrogate in review of the POLST, the orders should be followed. Review of

POLST, if feasible, is expected whenever the patient's condition changes significantly, the patient's venue of care changes, or the patient chooses to change his or her wishes. Thus, review is expected, but ignoring or overriding the POLST is not.

QUESTION: Is there an approach that would allow a single advance directive to meet all medical needs similar to how a single will functions? For example, if I complete and file an advance directive with my primary care provider, can it be applied to any provider? Are there unforeseen consequences of such an approach?

RESPONSE:

Most but not all states have reciprocity provisions in their advance directive laws that will deem an out-of-state directive validly executed if it was valid in the state where created. A presumption of validity is sometimes included in these provisions. In addition, we seldom hear of problems with provider's refusing to honor an out-of-state directive.

The more significant issue is how one's advance directive will be interpreted. States can vary in how they define terms in advance directives and how they will interpret specific instructions. The rules of interpretation in the implementing state will normally control. One illustration concerns the meaning of "authority to make all health care decisions for me." If that were the authority I granted in writing to my health care agent in Illinois, it would empower my agent to make all health decisions, including the withholding or withdrawal of life support or the decision to admit me to a nursing home. If I took that directive to Wisconsin, and my agent needed to act on my behalf, he or she would not be deemed to have authority over life support or nursing home decisions, unless I had specifically spelled that out in the directive.

Two years ago, under a grant-funded initiative to promote advance care planning, the ABA's Commission on Law and Aging set out to see if a single health care power of attorney could be drafted that would meet the legal requirements in the statutes of all 50 states and the District. The end product was able to accomplish that for most but not all states.¹⁴ In the end, there were five states for whom a "universal" advance directive could not work because of very particularized requirements within their laws.¹⁵

QUESTION: Are there legal concerns regarding when the advance directive was executed and last updated?

RESPONSE:

The issues of timeliness and accuracy of one's advance directive were touched on above. The legal issue that arises in this context is that of informed consent. Because an advance directive is typically done well in advance of a particular medical decision, it really cannot be

¹⁴ See, ABA Commission on Law and Aging, [Giving Someone a Power of Attorney For Your Health Care: A Guide with an Easy-to-Use, Legal Form for All Adults](#) (2011), available at www.americanbar.org/aging

¹⁵ The states were Indiana, New Hampshire, Ohio, Texas and Wisconsin.

expected to meet the standard of informed consent, which requires information and understanding about one's current condition, treatment alternatives, and their pros and cons. Thus, physician liability for lack of informed consent based upon failure to follow an advance directive is not a major risk. The role advance directives play is to provide some guidance to authorized surrogate decision makers and health care providers in meeting their obligations as surrogate decision-makers. Their obligation in most states is generally defined as following a standard of substituted judgment – i.e., deciding what the individual would have decided to the extent that can be determined – or in the absence of knowing the individual's wishes, deciding in the patient's best interests. The standard is very difficult to apply with precision, so by its nature, it is more aspirational than obligatory except in its gross violation. In other words, one can indeed face liability risk for callously ignoring an advance directive.

QUESTION: What legal initiatives have been implemented at the state level?

- Can you provide insight into the status of advance directives/POLST/POST/MOST at the state level (i.e., any legal or legislative requirements)?

RESPONSE:

Since the answer to this question deserves a whole article rather than a pithy response, I will refer to an article that I wrote on this subject that was published in 2010: "The Evolution of Health Care Advance Planning Law and Policy," 88(2) *Milbank Quarterly* 211-239 (2010).

- Do you have any concerns or opinion about these initiatives?

RESPONSE:

The beating heart as well as the Achilles heel of advance directives and POLST is the quality of the conversation between health care providers and patients or their surrogates. Physicians are not trained well to have these conversations and physicians cannot be expected to do it all, even if they were trained well. It requires a team approach that promotes ACP at multiple stages of one's normal health care.

- Is there a "floor" for compliance, and have there been sufficient analyses to demonstrate where states currently do not meet or currently exceed the "floor" established?

RESPONSE:

With respect to advance directives, there is no accepted or proposed floor in state practice. With respect to POLST, some broad benchmarks are emerging. For a state to be endorsed by the National POLST Task Force as a "mature program," a state must meet several requirements including the following:

The program is established statewide and there is widespread POLST

accessibility, use, and portability. The program is able to provide the following evidence:

1. more than 50% of hospitals, nursing homes, and hospices use the program in all regions of the state;
2. more than 75% of Emergency Medical Services (EMS) agencies have protocols that recognize and honor the POLST Paradigm form where there is statewide implementation of the POLST Paradigm program in all regions of the state;
3. the program offers an educational program with materials updated as needed and ongoing trainings that include the quality of the conversation health professionals have with their patients; and
4. there is an ongoing evaluation of the program that includes quality measures that evaluate performance with both research and QA/QI components.¹⁶

While there is no clear floor, there are models that show our expectations in most states are sadly too low. The La Cross, Wisconsin, example above demonstrates that it is possible for a health system to make ACP, including the use of POLST, the documented norm for nearly 100 percent of patients. In Oregon, a mandatory electronic registry for POLST forms was implemented in 2011, and it succeeded in screening and entering POLST forms into an accessible data base for more than 25,000 patients in just its first year of operation.¹⁷

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Thank you for the opportunity to share the views and expertise of the American Bar Association on this subject.

For additional information on these issues, or to tap into our membership expertise on these subjects, please do not hesitate to contact me at (202) 662-8686 or Charlie.Sabatino@americanbar.org or Thomas Susman, Director of the ABA's Governmental Affairs Office, at (202) 626-3920 or Thomas.Susman@americanbar.org.

¹⁶ See POLST program requirements at: www.polst.org/develop-a-program/program-requirements

¹⁷ See: Erik K. Fromme, et. Al., Research Letter: POLST Registry Do-Not-Resuscitate Orders and other Patient Treatment Preferences, 307(1) JAMA 34 (January 4, 2012).

ABA HEALTH DECISIONS POLICIES

The ABA has addressed patient self determination in health care in nine policy enactments.

(1) In 1986, the ABA House of Delegates recognized the "Uniform Rights of the Terminally Ill Act" (URTIA) promulgated by the National Conference of Commissioners on Uniform State Laws and amended in 1989. The URTIA was intended to promote uniform legislation for authorizing and implementing so-called "Living Wills." Because the URTIA was soon deemed to be too narrowly focused, the Uniform Law Commissioners replaced the URTIA with an expansive advance directive/surrogate decision making model in 1993, entitled the Uniform Health Care Decisions Act (UHCDA). The ABA officially recognized the new UHCDA by resolution adopted by the House of Delegates in February 1994.

(2) In February, 1986, the ABA House adopted a recommendation supporting legislation to expand the availability of Medicare reimbursement for hospice care services with the following language:

BE IT RESOLVED, That the American Bar Association supports the enactment of legislation which extends and expands the availability of Medicare reimbursement for hospice care services.

(3) In 1989, the ABA adopted the following policy encouraging the use and recognition of health care powers of attorney:

BE IT RESOLVED that the American Bar Association encourages the use and recognition of **durable powers of attorney** for delegating health care decision-making authority in the event of decisional incapacity of the principal. Steps to encourage such use and recognition include:

1. Explicit authorization in state law for recognizing delegations of health care decision-making authority under durable power of attorney laws of the enacting state or that of another state.
2. Procedures to ensure ease of use by the public, with appropriate protections to ensure that delegations of authority are made voluntarily with full appreciation of the consequences.
3. Regulations mandating all health care providers and facilities to (a) have policies in place regarding health care powers of attorney and other advance directives, (b) determine whether or not patients have prepared any such directive, and (c) inform patients of their legal rights to control health care decisions, including the right to appoint an agent or surrogate through a durable power of attorney.
4. Immunity from liability for health care providers who, in good faith and consistent with reasonable medical standards, act in accordance with a health care power of attorney.

5. Educational efforts to ensure that all adults have knowledge of health care powers of attorney and other advance directives and easy access to the means for establishing such directives.

(4) In 1990, the ABA adopted a resolution supporting the principle that individuals have the right to consent to and to refuse suggested health care interventions. Specifically, the policy states:

BE IT RESOLVED, That the American Bar Association supports the principle that individuals who are capable of making health care decisions generally have the **right to consent to and to refuse** suggested health care interventions, even if the result would be to shorten life's span;

BE IT FURTHER RESOLVED, That the American Bar Association supports the principle that an **appropriate surrogate** may exercise this right on behalf of an individual who is incapable of making such decisions. This resolution does not commit the American Bar Association to any particular position as to who are "appropriate surrogates," how they chosen or what standards govern their actions.

(5) The ABA adopted a resolution addressing physician-assisted suicide (physician aid-in-dying) in August 1997, as follows:

RESOLVED, That any consideration of the matter of physician-assisted suicide which involves personal, religious, emotional, medical, legal and ethical considerations and considerations of appropriate care alternatives, supportive services, pain relief, potential for abuse, legal protection, competency and needed research in many fields, should be left to be resolved by state legislatures and their electorates after extensive and informed public discussion.

FURTHER RESOLVED, That in the event that any state or territory chooses to adopt legislation permitting physician-assisted suicide, it should ensure that information and reporting systems are established to achieve close monitoring of the impact of such practices, especially with respect to vulnerable populations who may be particularly at risk if such practices are authorized.

(6) In August 1994, the ABA adopted a resolution supporting preemption of state law by any advance medical directive prepared for members of the Armed Forces:

BE IT RESOLVED, That the American Bar Association supports the enactment of federal legislation to provide that advance medical directives prepared for members of the Armed Forces, their spouses, and other persons eligible for legal assistance be recognized as lawful and given full legal effect notwithstanding state and territorial law.

(7) In August, 1995, the ABA supported better planning opportunities, including the use of advance medical directives, for people with HIV, AIDS, or other serious eventually fatal illnesses:

RESOLVED, That the American Bar Association supports action by federal, state, territorial and local governments to create legal mechanisms that allow people with HIV, AIDS or other debilitating, chronic, fatal illnesses to better plan for long-term care for themselves and their families, including standby guardianships, advance medical directives, and viatical settlements.

FURTHER RESOLVED, That the American Bar Association supports educational activities and other efforts designed to encourage implementation of appropriate legislation on standby guardianships, advance medical directives, and viatical settlements.

FURTHER RESOLVED, That where legislation is implemented concerning standby guardianships, advance medical directives, or viatical settlements, such legislation should contain appropriate consumer safeguards.

(8) At its 2000 annual meeting, the ABA adopted a policy supporting access to effective palliative care and review of controlled substances laws to ensure that they do not create unintended barriers to access to care:

RESOLVED, that the American Bar Association urges federal, state, and territorial governments to construe, apply, and if necessary, amend laws regulating the health professions, controlled substances, insurance, and both public and private health benefit programs so that these laws do not impose barriers to quality pain and symptom management.

FURTHER RESOLVED, that the American Bar Association urges federal, state, and territorial governments to support fully the right of individuals suffering from pain to be informed of, choose, and receive effective pain and symptom evaluation, management, and ongoing monitoring as part of basic medical care, even if such pain and symptom management may result in analgesic tolerance, physical dependence, or as an unintended consequence shorten the individual's life.

(9) In 2008, the ABA House urged widespread support of protocols such as Physicians Orders for Life-Sustaining Treatment that help ensure that patients' end-of-life care preferences are translated into visible and portable medical orders:

RESOLVED, That the American Bar Association urges federal, state, tribal, and territorial legislative bodies, governmental agencies, and health care providers to establish

and support decision-making protocols to ensure that the wishes, including those expressed in any prior advance directive, of those who have advanced chronic progressive illnesses are appropriately translated into visible and portable medical orders such as “Physicians Orders for Life-Sustaining Treatment” or “POLST,” that address higher probability medical contingencies, including hospitalization, cardiopulmonary resuscitation, artificial nutrition and hydration, antibiotics, and ventilation.

(10) In 2012, the ABA House urged strengthening of the Patient Self Determination Act as follows:

RESOLVED, That the American Bar Association urges Congress to amend the Patient-Self Determination Act (PSDA) provisions of the Medicare and Medicaid law to require that:

1. Every patient or patient’s authorized representative be given an opportunity to discuss issues relating to advance care planning with an appropriately trained representative of the provider organization within a reasonable time after the patient’s admission;
2. Health insurance exchanges developed pursuant to the Patient Protection and Affordable Care Act of 2010 be required under the PSDA to provide advance care planning information and resource options for follow-up assistance; and
3. In the absence of a validly executed advance directive, any clear, undisputed expression of a person’s health care wishes should be honored, as long as consistent with applicable law.

FURTHER RESOLVED, That the American Bar Association urges Congress and the United States Department of Health and Human Services to require the annual Medicare wellness examination, or other periodic doctor-patient interactions, to include both an opportunity to engage in and have resource options available relating to advance care planning for health decisions.

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January 11, 2013

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Re: Comments Regarding the Stage 3 Definition of Meaningful Use of Electronic Health Records (EHRs)

Dear Ms. Robertson:

On behalf of the American Bar Association, which has nearly 400,000 members, I write in response to the request for comments by the Health Information Technology Policy Committee on its draft recommendations for meaningful use Stage 3, which was published on November 26, 2012, at 77 *Federal Register* 70444.

Our comments relate specifically to SGRP 204B, SGRP 304, and SGRP 112, all of which address advance directives. The American Bar Association has a long-standing history of policy supporting the use and recognition of advance care planning tools, including support for health care advance directive uniform laws (1986 and 1994); health care powers of attorney (1989); better health care planning opportunities for people with HIV, AIDS, or other serious eventually fatal illnesses (1995); Physician Orders for Life-Sustaining Treatment (2008); and strengthening of federal law to give patients an opportunity to discuss advance care planning with health care providers after admission and as part of annual Medicare wellness exams (2012).

The ABA commends the Policy Committee for including the following elements that have the potential of supporting advance care planning efforts:

- SGRP 204B, a new menu item for including patient-generated health information in the record, such as advance directives; and
- SGRP 304, an objective for future stages to ensure care plan information is communicated in transitions across care settings, including information about the patient's goals of care and advance care planning documents, such as POLST and advance directives.

However, with respect to SGRP 112, the proposed objective and measures provide little in the

way of useful data, and may even do harm in light of research that shows that a significant proportion of providers make erroneous assumptions about the wishes of patients when told of the existence of a directive without details of its contents.¹ We recommend that this objective and measure be replaced by much more robust and relevant criteria in Stage 3, as further explained below.

Under SGRP 112, the Stage 3 Recommendation maintains the objective from the Stage 2 Final Rule: “Record whether a patient 65 years old or older has an advance directive.” The proposed measure for this objective is: “More than 50 percent of all unique patients 65 years old or older admitted to the eligible hospital’s or [critical access hospital’s] inpatient department ... have an indication of an advance directive status recorded as structured data.” As described below, this objective and measure miss the mark in supporting patient advance directives and other advance care planning tools in three ways.

The most salient shortcoming of SGRP 112 is the ineffectiveness of recording that an advance directive exists without any documentation of its contents or of the identity of a legally authorized representative for health decisions. The justification for not including the directive in the record in the Stage 2 final rule merely noted:

“As we stated in our Stage 1 final rule (75 FR 44345), we have continuing concerns that there are potential conflicts between storing advance directives and existing state laws.”
77 FR 53968-01

No further explanation of this comment was given. We have tracked and reviewed state advance directive legislation for over two decades and know of no legal barrier for hospitals or other health facilities to store advance directives in the medical record. Without documentation of the patient’s wishes or identity of their duly appointed surrogates, the goal of patient-centered care medical care, which is one of the statutory goals of the Office of the National Coordinator for Health Information Technology, is substantially undermined.² All patients should be requested to provide a copy of their advance directive, and it should be included in the record if provided by the patient.

The second serious shortcoming is the failure to capture the key components of advance care planning. Advance directives are just one component of documentation for advance care planning. A second component is advance care medical notes written or dictated by the physician that reflect a discussion with the patient regarding goals of care, treatment preferences, or related

¹ Ferdinando L. [Mirarchi](#), et al., “TRIAD III: nationwide assessment of living wills and do not resuscitate orders,” [J Emerg Med](#). 2012 May;42(5):511-20; Ferdinando L. [Mirarchi](#), et al., “TRIAD I: The Realistic Interpretation of Advanced Directives,” [J Patient Safety](#) 2008 December; 4(4): 1-6.

² “The National Coordinator shall perform the duties under subsection (c) in a manner consistent with the development of a nationwide health information technology infrastructure that allows for the electronic use and exchange of information and that-- *** (2) improves health care quality, reduces medical errors, reduces health disparities, and advances the delivery of patient-centered medical care;” 42 U.S.C.A. § 300jj-11.

decisions.³ In at least 15 states, if these medical notes are properly witnessed, they actually constitute a formal advance directive.⁴ A third component, now in use or in development in a majority of states, is Physician Orders for Life Sustaining Treatment (POLST), a vital care planning tool for patients with advanced medical conditions. The POLST Program, known by a variety of names,⁵ is a clinical process designed to facilitate communication between health care professionals and patients with advanced illness (or their authorized representatives) that facilitates shared, informed medical decision-making. The result is a set of portable medical orders that is applicable in all settings and across care transitions, is reviewable, and respects the patient's goals for care in regard to the use of CPR, breathing machines, and other interventions. Research on the POLST program confirms that it improves documentation of a range of treatment preferences and is associated with low rates of unwanted hospitalizations.⁶

The third serious shortcoming of the proposed measure for SGRP112 is the inadequacy of the target group as the denominator of the measure, which currently consists of all patients admitted to an eligible hospital or critical access hospital (CAH) who are age 65 or older at admission. While age is globally correlated to death and disability, it is a poor proxy of the need for advance care planning. Advance care planning documentation is most essential for adults facing advanced and eventually fatal illnesses. Many people in this group are younger than age 65, and many people age 65 or older are not in this group. The most accurate denominator to capture those in this target group is the number of patients who die during the reporting period. Most deaths today occur after a period of chronic, progressive illness,⁷ which should be a conspicuous trigger for advance care planning.

To address the concerns outlined above, we recommend that the required documentation in the record include a copy of the patient's advance directive, or advance care planning notes, or a copy of a POLST form. We also recommend that the meaningful use measure specify that a minimum percentage of adult patients who have died in the eligible hospital or CAH have an advance directive, or an advance care plan, or POLST in the medical record of the treating institution at the time of death. For Stage 3, we recommend that this percentage be set at least at the same level or higher than the 50 percent level set in the Stage 2 criteria.

³ P. Kernerman, D.J. Cook & L.E. Griffith, "Documenting Life-Support Preferences in Hospitalized Patients," J Crit Care. 1997 Dec;12(4):155-60.

⁴ Charles P. Sabatino, "The Evolution of Health Care Advance Planning Law and Policy," 88(2) Milbank Quarterly 211, 226 (2010).

⁵ POLST originated in Oregon, but examples of the program using differing names include West Virginia's Physicians Orders for Scope of Treatment or "POST" and New York's Medical Orders for Life-Sustaining Treatment or "MOLST."

⁶ Susan E. Hickman, et al., "A Comparison of Methods to Communicate Treatment Preferences in Nursing Facilities: Traditional Practices Versus the Physician Orders for Life-Sustaining Treatment Program," J Amer. Geriatrics Soc. 2010 Jul ;58(7):1241-8.

⁷ Centers for Disease Control and Prevention, "Chronic Diseases are the Leading Causes of Death and Disability in the U.S." See: <http://www.cdc.gov/chronicdisease/overview/index.htm>.

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One last consideration important to emphasize here is the timing of advance care planning. Measuring the documentation of advance care planning at time of death can be an unintended incentive for last minute initiation of advance care planning. To avoid or at least assess that result, it is important to look at the timing of advance care planning documentation. By way of example, one health system that has looked at such data as part of its effort to incorporate advance care planning into the fabric of its delivery system is the Gunderson Lutheran Health System in La Crosse, Wisconsin.

A retrospective evaluation of Gunderson's advance care planning processes published in 2011 found that 90 percent of a sample of 400 deceased patients had advanced directives, and 99.4 percent were available in the electronic medical record. On average, the directives were 3.8 years old. This compares to 1.3 years old in a 1998 study of the same practices, suggesting that advance care planning is occurring earlier in the patient population than had previously been the case. The study also found that 67 percent of decedents had a POLST form in the record. Because POLST provides a set of medical orders addressing the here-and-now status of patients with advanced care, these are expected to be initiated and reviewed as a patient's condition changes closer to the time of death. The study found that POLST forms were created a median of 4.3 months before death.

The ideal timing of various components of advance care planning depends on many variables, and existing research only suggests that too little occurs too late. For purposes of meaningful use criteria, we recommend that the recording of advance care planning documentation should include the length of time before death the planning documentation was created. This will provide a necessary marker for quality improvement.

In summary, we recommend that the Stage 3 meaningful use criteria include the objective "Record advance care planning status," which is met by the following measure: more than 50 percent of all patients who die in an eligible hospital or CAH inpatient department during the reporting period have at least one of the following in the record: a copy of the patient's advance directive, advance care planning notes, or a copy of a POLST form. In addition, we recommend that the record documents the length of time before death that the planning documentation was created.

Thank you for considering the views of the ABA on these important issues. If you have any questions regarding the ABA's position on the proposed rule, please contact me or Charlie Sabatino, Director of the ABA's Commission on Law and Aging, at (202) 662-8686.

Sincerely,

A handwritten signature in black ink, appearing to read "Thomas M. Susman", with a long horizontal flourish extending to the right.

Thomas M. Susman